The Iowa Blind History Archive
History of Blindness in Iowa - Oral History Project
Interview with [Name]
Conducted by [Name]
[Date]
Transcribed by [Name]

NOTE: Any text included in brackets [ ] is information that was added by the narrator after reviewing the original transcript. Therefore, this information is not included in the audio version of the interview.

Susie (Susan) Stageberg, 59, Clive, Iowa
Meredith Ferguson
Iowa Department for the Blind building
524 4th St., Des Moines, Iowa
March 29, 2011, 8:35 A.M.

Meredith Ferguson: Susie and I work in the same building, but other than that we really don't know each other. The purpose of the interview is that it will become part of the

Iowa Department for the Blind's History of Blindness in Iowa, Oral History Project. Just to be clear, Susie, do I have your permission to record this interview?

Susie Stageberg: Yes, ma'am.

Ferguson: Okay. Before we get started could you state your full name, where you currently live, and your age?

Stageberg: Susan Stageberg; only people who are mad at me call me Susan, and Harlan. (Laughter) I'm 59 and I live in Clive.

Ferguson: First off would you tell me where you were born and grew up, and a little bit about your parents and if you have any siblings?

Stageberg: I was born in Philadelphia. My Dad was there. Very early in their marriage they lived in Philadelphia for about a year. Then they moved to Illinois and had my sister. I grew up in Illinois, went to high school and college, started college there. My parents are sill living and they live in Champaign, Illinois, which is the home of the "Fighting Illini" from the University of Illinois. The rival of Iowa.

Anyway, I went…first I went to a small Lutheran church supported college in Rock Island, Illinois and then I went to the University of Illinois for a year. I didn't like that big place; then got married. My husband was studying to be a pastor. This was husband number one. He spent his internship in Kalamazoo, Michigan. At that time, I finished my bachelor's degree at Western Michigan University. After

that we moved to Chicago; we were living in Chicago. That is where the seminary is.

While I was in Chicago, I worked at the Sears Tower for Sears and Roebuck in word processing. In those days not everybody could word process on their computer. So, this was a machine that recorded your document onto a card about like, a computer card. And, then you fed the card into a great big printer. It was the size of a small house! And, it printed your document out. Now, everybody, Tom, Dick and Fred, can word process at home and everybody has their own printer. In those days, it was a big deal. It was a typing pool basically.

Ferguson: What was your Bachelor's in?

Stageberg: I had majored in French and a minor in Social Work. I never did the student teaching, so I don't have a teacher's certificate.

Ferguson: Could you tell me how long you have been blind and what caused it?

Stageberg: I've been blind since birth and it's Retinitis Pigmentosa. That is supposed to be genetic. Nobody in my family before or since has it. So, it's pretty weird. When I was thinking about having family, I had a doctor who suggested that I get a, "You should really go to Iowa City and have a workup and…" Susie said, "And, what's that going to tell me?" The doctor said, "Well, it's going to tell you that the baby might be blind." Susie says, "Well, yeah, I already figured that out; besides, so what!" So, I don't know

all the gory details of why that happened to me, but that's what it is.

Ferguson: So, you got married a second time? You said you had a first husband.

Stageberg: Um-hum.

Ferguson: Is that…are you currently married?

Stageberg: Yes.

Ferguson: Okay. How did you meet him? Do you have children?

Stageberg: I have four children. Two from each marriage. The older ones are 28 and almost 25. They share an apartment in Des Moines. And, then the younger ones are 15 and 14.

Ferguson: Oh, teenagers.

Stageberg: Yeah, teenage girl and teenage athlete, hollow leg jock boy. (Laughter) I met my current husband, he was the choir director at church and I sang in the choir. That's how we met. They always tell you church is a great place to meet people.

Ferguson: There you go.

Stageberg: There you go.

Ferguson: Is he blind?

Stageberg: No. Neither one.

Ferguson: Okay. Do you…I should ask, do you have anything specific that you would like to talk about or share any particular stories? If not, I'll just ask some of the questions.

Stageberg: There is one thing. When I was married the first time and the kids were really little, I discovered that the library was here in town. The library had a whole room full of children's books that had pictures and Braille and print. We came down here, the kids and I with a great big canvas bag and we went home with about twenty books. We'd pile them on the bed and we read all afternoon. It was so cool because they were getting to the point that I couldn't memorize their little board books anymore; and the same ones over and over again. I let them help me pick. We just had the best time and they still remember that. "Oh, yeah, we used to go to the library!" So, that was my introduction to the library upstairs, which is now…I help people find that room full of books.

Ferguson: How did you come to Iowa?

Stageberg: My pastor husband's first parish was in Sioux City. So, after seminary we…in 1979 we moved to Sioux City. We were there about four or five years.

Ferguson: Do you remember what year that was?

Stageberg: Um…we came here in 1985, I think. Yeah. My son was born when we were up in Nevada and then we moved down to Des Moines in '88.

Ferguson: Okay. So, did you know about the Department and the Library very specifically right away or how did you?

Stageberg: I knew about the Department because Roger Erpelding was my Rehab. Counselor. At that time, there was a Sioux City office. When I lived in Sioux City he helped me find my first job in Iowa. He and I could tell you some rip-roaring interview stories.

Ferguson: Oh, yeah? Do you want to share one? That sounds interesting.

Stageberg: (Laughter) He went with me to an interview at this place called Advanced Industries. He went along to kind of explain how, you know, they wanted a receptionist. How was I going to do this? So, we talked for two hours to this woman, who was the personnel, nowadays she'd be Human Resources Director. We explained how I could bring the coffee and answer the phone and do all this stuff and at the end of it she said, "Well, I really need an application filled out." And, Roger said, "Well, that's fine. We'll take it home and Susie can have a reader help her fill it out." And, the woman says, "You mean you can't read or write; either one?"

Ferguson: Oh, wow!

Stageberg: (Laughter) I'd explained all about Braille and, you know, the whole thing and she…"You mean you're illiterate?" When I ran into him here I said, "Oh, how about going to Advanced Industries?" He remembered. (Laughter)

And, I knew there was a library and I had borrowed from the library, through the mail like most people do. When I ended up in Des Moines, wow, I can go in there and actually take them home with me.

Ferguson: I guess backing up a little bit, for your education you went to public school?

Stageberg: Yes.

Ferguson: Could you tell me a little bit…you've been blind since birth. So, did you…what kind of skills did you use to help you through or was it, did you find it more difficult at times?

Stageberg: We had a…nowadays they call it a TVI, a Teacher of the Blind. The school system I was in was the Champaign, Illinois school system. They started kind of with me, having blind kids in the school, now known as mainstreaming. Kids came from all the area around Champaign to go to school there; blind kids did. We had the room, the Resource Room, Braille Writers, Tactile Maps, the World Book Encyclopedia in Braille, which is 144 volumes. Lots of times the textbook didn't arrive until…the Braille textbook, didn't arrive until half way through the year. I remember that happened in Geometry. I took Geometry in the ninth grade, like everybody did, but the book didn't come until January. And so, until then my Dad was the Geometry

tutor. And, since he aced Calculus in high school, he could not figure out how this offspring of his could be so dumb in Math! "What do you mean you don't get it?" Dread.

Plus, he always wanted to do Math when I wanted to watch something on TV. At the time, you know, in my ninth grade mind I thought, "He's waiting until the Beatles were on Ed Sullivan and then he's going to make me do Geometry." Could have done it an hour ago, but no...So, a lot of times I didn't have the book that the other kids have.

I see now that the IMC upstairs turns them inside out to get the kid's books on the first day of school. Those kids are really lucky. So, there were, of course, some things available in Braille and yeah, it's harder. The thing, I think, this mainstreaming is going to make the sighted kids and the blind kids get along better. That's one of the side benefits supposedly, I wish.

You know, children can be very accepting and they can also be very cruel. I had instances of people moving my desk. In the second grade I was locked in my locker by some little sighted kids. Yeah, I wouldn't say I was a social success. So, therefore, I think I probably feel like that's equally important as academic success for the blind kids in the public school. Because when you get out of school you don't need to know necessarily Geometry, you need to know how to get along with people. To see some of these kids come in here and they don't know how to get along with people. The transition students or even some of the kids that come into Orientation just are not socially very adept. I don't know how you fix that.

At the time I was in school, the school for the blind was just, it was just people who were just blind; like Mike Barber and Karen and people like that. Nowadays, if you are there

it's because you have 915 different things the matter with you and' Cerebral Palsy. And so, it's not the same atmosphere. There is something to be said for going to the school for the blind with other high functioning blind kids because then you learn all that blind stuff; the cane and how to make the bed and all that, how to cook grilled cheese. Mike and Karen got to be in a play. I wasn't in a play. They got, they had Gym class. I sat and watched Gym class because they were afraid for me to hurt myself. I probably, maybe got a better, probably got a better education, but there were some other things. I didn't have boys asking me to go out until college.

Ferguson: The social aspect is really an important part of growing up and shaping character.

Stageberg: Yeah. I'm not sure that there's one answer to it. It's for sure that mainstreaming doesn't fix everything. It may be the better of the two choices, but judging by some of the products I see, people coming in here, it doesn't do the social thing. It doesn't always do the academic either. Not that I have any opinions. (Laughter)

Ferguson: So, high school was iffy.

Stageberg: Yeah, I did fine. I was in the Honor Society. I did fine. I was probably in the top 10% of my class. I had a friend or two. Nothing like what I would call "normal." Nothing like my sighted daughter has.

15:00

Ferguson: Did it get any easier once you got to college?

Stageberg: Well, the thing that got easier in college…The textbooks and things got harder because a lot of them were not produced by anybody. What there was on reel-to-reel tape? This is how old I am. (Laughter) But, the social thing got much easier. I think it's just that transition from being high school kids to being in college and being away from home, and everybody just got more tolerant and more open minded.

So, I had a blast at the Lutheran School, the first place I went to school. I was in a Sorority and I had dates, you know, this was like, wow! Who has time to study? I'm busy. So, for various reasons I dropped out after I went to the Illinois for a year. Then when I finished at Michigan, I did it all in one year. I used a lot of readers. Recording for the blind didn't always have what I needed because I majored in foreign languages. And so, you'd hire somebody from the class who was very good to read to you. They were reading it anyway. You know, I got through.

Ferguson: Let's see, I'm just kind of going down my list.

Stageberg: Sure.

Ferguson: So, tell me a little bit more about your current job. I know you are a Reader Advisor. Is that right?

Stageberg: Um-hum.

Ferguson: Okay. Tell me a little bit about how you got the job here and a little bit about what you do.

Stageberg: Well, I came to work here ten years ago. I wasn't a Reader Advisor then. I was in Braille Production. Actually at some point in my at-home mom years, Rosie asked me to be on a panel for a conference she was doing with Karen Keninger. It was me and Karen Keninger and this other gentleman. I met Karen; I had not met her before, and thought, "Wow, this is somebody I would really like to know better." And, kind of kept in touch; sort of.

So, when it became clear that I was going to have to get a job because we needed a bigger house, therefore, we needed more money. I contacted Rosie and Rosie said, "They're looking for somebody up in the Library, so you should apply for that. I went to work up there in Braille Production as a Clerk doing data entry and embossing Braille material. Sort of what Sarah Cranston does now? I did not know before all this process, I didn't know a computer from a hole in the ground. So, the Project Assist Grant folks brought me a computer, brought me the tutorials for Word and Windows and stuff and I did that at home before I applied for the job. Then when I got here I found out how much I really didn't know. Karen very kindly and patiently sort of brought me along. "Do you know how to do that?" "No." "Okay, come to my office at 10:30 and I'll show you how to copy files onto a disc." So, she worked with me. She wanted it to succeed.

So I did that for a couple of years and then Project Assist got a Grant to write tutorials for deaf/blind people. They needed a Documentation Specialist; they called it, a Technical Writer. I applied for that and worked down here for three years until that Grant went away. And, about that time, one of the Reader Advisors upstairs retired…is that

right…or she took another job. Yeah, it was Gail. She took another job. So, I jumped in there. I don't have Library Education, but I read, read, read, read, read, read. So, it just worked out really well that it came at the right time. I like being a Reader Advisor.

Ferguson: What do you like about it?

Stageberg: I really…I like knowing that people's lives are better because of what I do. Most of my folks are elderly people, shut-in kind of…or they think they are shut-in. They wouldn't have to be but they are loosing their vision, and so maybe they were avid readers when they could see and they think, "Oh, I can't read anymore." Well, yes you can. Some of them will call me and say, "Oh, I just hate TV. I just hate daytime TV. So, please send me more books. I read a book a day." I love that. By the same token, if the mail gets bogged down and they don't get their book a day, then I hear from them. But, a lot of times they call and complain and what they are really complaining about is I can't see anymore. But, that's…what they say is, "What are you people doing sending me all that filth?"

Ferguson: Oh boy.

Stageberg: But, I like making a difference. I think it's my favorite story is the lady who said, "Oh, you know, I used to knit all the time. And, I just knitted things for grandchildren and everything and now I can't see, I can't knit anymore." "Yes, you can. I knit and I can't see." "You do?" I said, "Yeah. Not only that but I belong to a group, an on-line group, of blind knitters. You can do this." I said, "You do it

without lookin'. You think you have to look but you…didn't you knit while you were watching TV?" "Well, yes." "Were you looking at your stitches?" "No." "So, your fingers remember how to do this. So just go for…" "Oh, could you send me a knitting book?" "Sure."

Ferguson: That's awesome.

Stageberg: Little stuff like that happens, oh, pretty regularly. You show somebody they can do something they didn't think they could do.

Ferguson: Well, you have four children. You mentioned you were a stay-at-home mom for a while?

Stageberg: Yeah.

Ferguson: I'm just interested in maybe some of the techniques you used to corral your children? I'm imagining some rambunctious kids.

Stageberg: Do you? Yeah. You listen, you listen, you listen and you listen. Your brain never goes off-duty, which I would maintain makes it more trying. You cannot look across the room and see, "Oh, he's okay or oh, he's about to get into that." You have to listen and if you hear a sound you don't recognize you have to go and investigate. And, worse yet, if you hear no sound then you really have to go investigate. Nobody ever broke a bone on my watch. They got away with things. If you told…If I said clean your room more than once they shoved everything under their bed or in

the closet which became readily apparent when you opened the closet, it all came falling out. (Laughter)

One of them drew on the wall with permanent marker once and I had no idea. I put her to bed. I was all happy with her and then her father came home an said, "Who drew that on the wall?"

They undoubtedly got away with stuff. But, you know, I figured it balanced out because I caught them and sometimes I accused them of things they weren't doing. So, it balances out. It's like officiating at a football game. You get a few good calls and a few rotten calls, but they all kind of even out.

I would just say, "Listen and you have to anticipate. If I leave that down, somebody is going to get into it." You can't just be careless, because oh boy, they are going to find whatever it is. I raised them in sets of two. You know, I had all four of them at home at one point, but the two older ones were in college or in high school, which is a whole different disciplinary. "No you can't bring your boyfriend up to your room! I know he's in there. Get him out of here! Sorry Michael, you can't be up there." Of course, now she tells me, "Oh yeah, he was there a lot that you didn't know about."

Ferguson: It all comes out now. (Laughter)

Stageberg: (Laughter) Un-huh. Let's see, that's the main thing. Good baby proofing and listen, listen, listen, listen…it can be done. It's not, oh, how can I take care of the baby? You can. The only thing I never, I couldn't manage on my own, was the eye drops that the one kid had to have one time for pink eye. They were cortisone drops and they

stunk, and so he did not sit patiently for me to drop these into his eye. He was two. So, that I made his father do it. But, otherwise I administered medicine, I fed them, I washed their clothes, I combed their hair. All that stuff; they were well cared for. Like I said, the only broken bone we ever had was when their father was watching and I was nowhere around. So there, hah!

Ferguson: What kind of fun things did you do with them when they were little, I mean, still now?

Stageberg: Well, like I said before, we read a lot. We played games. They were big Sesame Street fans. You think, "Oh good, Sesame Street is on, I'm going to go make dinner." Well, you're half way through making dinner and one of them yells, "Mom come here. Bert and Ernie are making the bed." And so, I would come in there and I would end up sitting and watching with them. And so, we watched movies. We played games. We read books. The usual stuff that you do. We played outside.

Ferguson: Did you ever, I guess get…how do I say this…did you ever feel like you were censured for being a blind mom with the sighted children?

Stageberg: You know, the kids probably suffered more of this than I did. Every one of them has been asked by their classmates, "Well, you're mom can't do anything, how can she even have sex?"

Ferguson: Wow!

Stageberg: "Hello! Do you do it with the lights on? Excuse me!" I have tried with each of them to go into their class and bring the dog when I had a dog and talk about blindness and how I do stuff. With the older children I walked and picked them up from school. Their father dropped them off and I would go there with the dog, and I would go at the end of the school and escort them home. Their classmates saw me every day. I don't sensor I don't thing so much as…and this is almost as bad. "Oh, isn't she just amazing?"

I will say that when one of them was born, up at Methodist, the Pediatrician came in the day we took her home and said just like this, "Well, I think you're going to be just fine at home." From that I deduced that a meeting had been held and that somebody had said, "How is she going to take care of that baby?" It was my third baby. I sort of knew which end you put the diaper on. Nurses are sometimes the worst. I don't know why that is, but they just…once in a while I'd get one who would get all in a tissle because I had this baby. I think they probably assumed that the sighted husband was really going to do all the work.

I know that in my husband's church when the first one was on the way I overheard a conversation. "Well, you know she's showing she's really pregnant. I guess we're going to have to give him a raise and hire a nanny because she's never going to be able to take care of that baby herself."

Ferguson: Oh.

Stageberg: There's nothing you can do about that except show up with her every Sunday morning dressed, fed, combed, you know, matched pink socks matching the pink dress. All you can do is do what you do and show them.

And, even then I think there are some people who are beyond showing. Their brains are set.

I've sung in the church choir over here at St. John's for 15 years, and there is still somebody who says, "Oh, look the little blind girl in our choir is here." Grey haired 60-year-old woman…little blind girl. That's not parent, that's just, you know, blind equals helpless and I think more important, "Oh, what would I do if I were blind?" I think that's people's knee-jerk reaction. "Oh God, I'd never make it. I'd be helpless." Therefore, she must be helpless. Therefore, let me help her across the street, even if she wasn't crossing the street. So, yeah it's an adventure sometimes. It's kind of fun to work around here in a way because nobody says that.

30:00

Stageberg: You can get your meeting agenda Brailed if you want. (Laughter) It's not, "Braille, what's that?" On the other hand, we all know what blind people can do around here so we don't put up with a lot of slacking. So, it's mixed. It's a mixed…Karen told me when I came to work here, "We don't hire just any old blind person." So, there you go.

Ferguson: Are you involved…I know you sing in the choir. Are there any other community activities that you do?

Stageberg: I sing in my church choir and I also sing in a community choir that's auditioned only. It's a group of 36-37 people. We give concerts throughout the year. I learned Braille music notation when I was 12.

Ferguson: Could you explain what that is?

Stageberg: Well, it's a system for writing music in Braille. You don't have lines and spaces and notes like print music has. It's a code. Now, what I do to keep up with these two groups that I'm in is I Braille my own music. My husband is a singer, too, so he dictates. "In this measure we have three quarter notes and a half note and we have "C," "D," "E" So, I write it out. I used to just learn music in rehearsal and learning by rote, but in the church choir they pay me to be the section leader, which means I am supposed to know what's going on. People are supposed to sit in rehearsal and follow me. I couldn't do it if I didn't have the skill to do Braille music. I couldn't do it all by ear anymore. It's too much. It moves too fast and my brain is not as nimble as it was. That's pretty much what I do. Between that and working full-time, I'm not out there volunteering too much.

Ferguson: What do you like to do…is that what you do for fun, too?

Stageberg: Yeah, yeah that's the thing he and I do that's not kids and house and work. It's very good. I like to knit. I love to read. I like to cook when I have time. Working full-time kind of put me out of the chef business, but on weekends I cook. I spend time with my grown-up kids and the little ones, too. Although, they are at the age when they don't really want to spend time…unless we're going clothes shopping and she needs my credit card. "Oh mom, I want to spend time with you. Let's go to the mall!" Yeah, right. "How about this, I'll give you this money and you go to the mall."

Ferguson: I guess I didn't ask where…I notice you use your cane and you also have a dog. Where did you learn your skills? Did you…have you always done cane travel?

Stageberg: Um…in junior high I spent a summer at a place in Chicago, Illinois. It was called IVHI. Illinois Visually Handicapped Institute. It is not our Orientation Center. It's not anywhere's near, and the philosophy's not the same, but I spent a summer there and I learned cane travel. And so, I pretty much caned…when I'm in college used the cane.

A real good friend of mine got a guide dog, somewhere along in there, and I saw how easily she got around and decided I wanted one of those. So, I was probably 25 when I got the first one. I've had three. This current one came from the Seeing Eye in New Jersey, like Karen's dog. He's just recently retired. He's 10 years old and he was slowing down and kind of…he's now a doggie couch potato. We kept him because I couldn't bear to part with him. He obviously wasn't wanting to do his work anymore, so we just called it quits.

There are differences between traveling with a cane and traveling with a dog. When you travel with a dog, the dog will take you around things like poles and garbage cans and people standing in the sidewalk. You're going to hit all of that with your cane. Some people like all that feedback from their environment. They don't want to be whisked around it. They want to know that that pole was there. I'd just a soon gracefully go down the block and, well, it's a partnership. That's good for you, you know, to work together. It's an equal partnership. He makes some of the decisions; I make some of the decisions.

It's not like I'm an idiot and that brilliant dog is leading me around. It's not like I have this dog to protect me. He's a Lab. He's about as un-ferocious as you can get. But he, like I said, he makes the small decisions. Let's go around this barricade and I'm the one who knows where we are going. I think a lot of people don't understand how it works with a blind person and a guide dog and have misconceptions, especially blind people. It's like 10% of blind people who use dogs. I can do it with a cane, you know, I can. So, it's not that I have to have a dog. I like having a dog.

Ferguson: What kind of, you mentioned misconceptions about guide dogs. What…can you explain that?

Stageberg: Like I said, people think that the dog has all the brains. I've been asked, "Does he read the street signs?" "Hello!" "Can he bark when the light is green?" "No!" I had somebody ask me on an "L" platform in Chicago, "I was going to help you, but I figured your dog barked once for the "A" Train and twice for the "B" Train and three times for the Evanston Express. Is that right?" "No!" You know people think it's wonder dog. He can do everything and you're just hangin' on for dear life. That having a dog means you don't have good travel skills. That's not true at all. As a matter of fact, if you're lost and wishy-washy and not knowing where you're going you're going to confuse the dog. You need to be in charge of the route. We're going to go here, left. Then we're going to go up here where I smell Dominoes and then we're going to go right. And so, again, people assume you're helpless. So, if you have this dog it must be you need the dog as your savior to fix your blindness, which is just…, he's

a tool. He's a lovely, furry, tail wagging, floppy eared tool who licks my face. But, he is a tool. I tell him what to do.

There's the access things about..."You can't bring that dog in here." "Oh, yes I can." They give you...most guide dog schools I know about give you a book when you graduate that has all the state guide dog laws in it. If you have to you can whip that on somebody and all I've ever had to go into my purse as if I was going and say, "Would you like to see the law?" And, boy then they back right up. But, you know, people in restaurants, "You're not suppose to bring your dog in here, its unsanitary." Well, I can bring him in here." Oh, I can bring in into the hospital I can bring him on the airplane. It's a matter of not being educated. And so, you kind of end up being the ambassador of the world of the blind guide dog user. Which is like...oh please will you just get it and not make me explain it? I always thought I would make a tape and just play the tape kind of on a loop. "Don't pet him. Please, don't pet the dog. Yes, he can come in the restaurant. No, I don't need help just 'cause I'm blind." Save my breath!

Ferguson: Do you have anything else you would like to add?

Stageberg: I think this was a good list of questions. I think you've probably plumbed all what I know. (Laughter)

Ferguson: Thank you, again, very much for sitting down and doing this interview. We'll have it transcribed. Would you like a copy to read through the transcription before we post it?

Stageberg: Yeah, I would.

Ferguson: Would you like it in Braille or I can e-mail a version to you.

Stageberg: E-mail it.

Ferguson: Okay, I can do that.

Stageberg: Let's save a tree.

Ferguson: Good plan. Okay.

(End of Recording)
39:56

Deb Brix
May 22, 2011